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**Limited availability of cardiac rehabilitation for heart failure patients in the United Kingdom:
findings from a national survey**

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Abstract

Background: Participation of patients with heart failure in cardiac rehabilitation in the UK is low. This study investigated the availability of cardiac rehabilitation services for patients with heart failure in the UK and the views of service coordinators on ideal service models.

Design: Our study was a cross-sectional national postal survey that was mailed to 342 service coordinators in the UK between April and June 2009.

Methods: We developed a 38-item questionnaire to survey all cardiac rehabilitation service coordinators on the National Audit of Cardiac Rehabilitation register in the UK in 2009.

Results: The survey response rate was 71% (244/342). Forty three per cent (105/244) of coordinators did not accept patients with heart failure to their cardiac rehabilitation services. Most coordinators who did accept patients with heart failure offered their services to patients with a variety of cardiac conditions, though referral criteria and models of care varied widely. Services inconsistently used New York Heart Association classes and left ventricular ejection fraction measures to select patients. Few offered separate dedicated heart failure programmes (14%; 33/244) but where these existed they ran for longer than programmes which included patients with heart failure alongside other cardiac patients (10.9 vs 8.5 weeks; $F = 4.04$; $p = 0.019$). Few offered home-based options for patients with heart failure (11%; 27/244). Coordinators accepting patients with heart failure to their cardiac rehabilitation services tended to agree that patients with heart failure should be included in services alongside other cardiac patients ($\chi^2 = 6.2$; $p = 0.013$).

Conclusions: There is limited access for patients with heart failure to cardiac rehabilitation in the UK. Local policies on referral and selection criteria differ and reflect coordinators' views rather than clinical guidance.

Key words: Heart; heart failure; physical activity; exercise; rehabilitation; patient care

Introduction

Despite rapid advances in treatments for patients with heart failure over the last 20 years, many patients receiving medical treatment still experience unrelieved symptoms resulting in disability, poor quality of life and shortened life expectancy. Due to the combined effects of ageing populations and improved survival after myocardial infarction (MI), the number of patients with heart failure is set to rise.¹ Improved survival after diagnosis² suggests that heart failure management can only increase as a concern for patients, doctors and the healthcare systems worldwide.³

Many international clinical guidelines recommend that people with heart failure undertake exercise training as part of their treatment.^{1,4-6} A Cochrane systematic review of exercise-based rehabilitation for heart failure (including 19 randomised controlled trials (3647 subjects)) confirmed that exercise training improves health-related quality of life for patients with both mild and moderate symptoms and reduces heart failure-related hospitalisations.⁷ Yet findings from the European Cardiac Rehabilitation Inventory Survey described the provision of rehabilitation for patients with heart failure in only a minority of European countries.⁸

In the UK, the National Audit of Cardiac Rehabilitation (NACR) audits the total numbers and diagnoses of patients participating in cardiac rehabilitation services. The majority of patients attend after cardiac surgery or MI. Since 2007, annual audits have consistently demonstrated that only around 1% of cardiac rehabilitation attendees are participating because of heart failure.⁹ Furthermore, data from the National Health Service (NHS) Heart Failure Survey in England, Wales and Northern Ireland found <1% of 9387 patients admitted to acute NHS hospitals were referred for rehabilitation.¹⁰ Therefore the potential considerable health gains for patients with heart failure remains unfulfilled, despite supportive evidence and recommendations for participation.

Studies investigating predictors of referral and adherence to cardiac rehabilitation for MI and cardiac surgery have highlighted that both health service-related factors and patient-related factors are associated with participation.^{11,12} However, those with heart failure are underrepresented in cardiac rehabilitation research.¹³ British health service-related factors such as availability of cardiac rehabilitation services for patients with heart failure and service acceptance of referrals need further investigation to guide remedial action.

We conducted a study to explore two potential health service-related explanations for the current low participation of patients with heart failure in the UK's cardiac rehabilitation services: (a) a lack of availability of cardiac rehabilitation services for people with heart failure including service coordinators' views on ideal service models and (b) inadequate referral processes.

Methods

We developed a 38-item questionnaire with open and closed questions covering aspects of both general and heart failure-specific cardiac rehabilitation service provision (see Appendix 1). The questionnaire was designed for the service coordinator (i.e. the senior clinician who has the responsibility for coordinating, managing and evaluating the service).¹⁴ The questionnaire used terminology familiar to UK service providers including the Phases of cardiac rehabilitation. In the UK these are: inpatient provision (Phase I), the immediate period following hospital discharge (Phase II), group and/or home-based cardiac rehabilitation provision (Phase III) and the adoption of long-term behavioural changes (Phase IV).¹⁵ Questions examined the referral processes, inpatient screening, service availability and type, such as home- or hospital-based outpatient care and details of cardiac rehabilitation for patients with heart failure. The questionnaire examined the total referrals received in one month (1–31 March 2009) for all patients to Phase III cardiac rehabilitation and for those with heart failure. Coordinators' views were ascertained through their agreement (5-point Likert scale) to a series of statements about service models and commentary boxes. Content validity was established by multidisciplinary expert panel review (18 people including cardiologists, geriatricians, cardiac rehabilitation and heart failure nurses, allied health professionals, survey methodologists and a previous cardiac rehabilitation patient) and through piloting. The survey, including a repeated mailing to non-responders, was distributed to all 342 service coordinators on the NACR register between April and June 2009. Ethics approval was granted through the local NHS National Research Ethics Committee (NRES) (Reference Number: 09/H0802/16).

Statistical analyses

Quantitative results are summarised using descriptive statistics and all percentages reported relate to the entire survey population, unless otherwise stated. Not all questions in the survey required a response from all coordinators; therefore, percentages reported for some items are based on all valid responses. Differences between groups were tested using the χ^2 test for categorical data. One-way analysis of variance (ANOVA) was used to test differences in the mean duration (in weeks)

across the three different service models of cardiac rehabilitation for patients with heart failure. For all analyses $p \leq 0.05$ was considered significant except for testing differences in the mean duration (in weeks) across service models where $p \leq 0.025$ was used. Quantitative analyses were performed with SPSS for Windows (version 17.0). Qualitative analyses of responses to open ended questions and commentary boxes were facilitated using NVivo 8 software (QSR International Pty Ltd: version 8.0).

Results

Description of respondents

Questionnaires were returned by 244 of the 342 service coordinators contacted (71% coordinators). The response rate varied across the UK (England 189/271; 70%, Scotland 26/36; 72%, Wales 16/20; 80% and Northern Ireland 13/15; 87%). Coordinators were: nurses (203; 83%), physiotherapists (22; 9%) and other health professionals (19; 8%) including occupational therapists, psychologists and exercise specialists.

Few coordinators (14; 6%) reported that all the recommended professional constituents 14 were funded in their service. Staff members specifically funded were predominantly cardiac rehabilitation nurses (224; 92%), physiotherapists (152; 62%), secretarial/clerical staff (133; 55%), physicians/cardiologists (26; 11%) and heart failure nurses (2;<1%).

Coordinators reported their services were running at full capacity (95/244; 39%) or had a waiting list (76/244; 31%). However, some coordinators (49/244; 20%) reported having capacity to accept more referrals.

Cardiac rehabilitation availability

Patients with heart failure were not universally accepted by coordinators to their services (Table 1). Patients with heart failure were accepted across all locations with variation by country (Table 2). Over a quarter of coordinators (63/244; 26%) reported lack of funding as the main reason for not providing a specific service for patients with heart failure. Additional reasons reported included: lack

of time (24/244; 10%), lack of facilities such as venue availability (17/244; 7%) and lack of staff (4/244; 2%) (categories not mutually exclusive).

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Inclusion and exclusion criteria

One hundred and three coordinators reported over 77 inclusion and exclusion criteria for patients with heart failure. Full responses on inclusion and exclusion criteria are provided as online supplementary data (Appendix 2 online). Criteria based on echocardiography measures, such as left ventricular ejection fraction (EF), were extensive, discrepant and contradictory. For example, EF <40% was reported as both an inclusion and an exclusion criterion. Coordinators were divided about using the New York Heart Association (NYHA) classification as an acceptance criterion (75 did and 73 did not). There was a variety of NYHA stages used as inclusion criteria: NYHA I and II only (n = 21), NYHA I, II and III only (n = 41), NYHA II and III only (n = 7) and NYHA II, III and IV only (n = 3). Functionally limited patients (NYHA class IV) were least often accepted.

Other criteria reported related to patient safety, such as excluding patients with unstable heart failure and cardiac arrhythmias. Seventeen coordinators reported patients were only accepted if they had been on optimal medical therapy for approximately 1 month.

Referral processes

Findings on referral processes for patients with all cardiac conditions and those with heart failure are reported as n (%) providing for all conditions, followed by n (%) for heart failure respectively (categories are not mutually exclusive). Methods of referral were: paper referral form 214 (88%), 104 (43%); doctor/health professional referral letter 211 (86%), 129 (53%); cardiac rehabilitation staff screening wards 190 (78%), 56 (23%); telephone/pager referral system 135 (55%), 56 (23%); secure email system 78 (32%), 27 (11%); automated electronic system (e.g. electronic patient record) 27 (11%), 14 (6%). The few services operating automated electronic referral systems were diverse and included community centres, acute teaching and district general hospitals. There was a significant association between electronic referral availability and accepting patients with heart failure for cardiac rehabilitation ($\chi^2 = 3.922$; $p = 0.048$).

Among the 151 (62%) coordinators who described the professional groups referring to their services, most reported cardiologists (111; 74%) or heart failure nurses (98; 65%) referred patients with heart failure. Others reported to refer these patients were: community heart failure nurses (95; 63%); cardiac rehabilitation nurses (60; 40%); general practitioners (55; 36%); ward nurses (40; 26%); general internal medicine consultants (27; 18%); physiotherapists (22; 15%); geriatricians (21; 14%) and coronary liaison nurses (15; 10%). Patients could refer themselves in 27 (18%) centres.

Staff members screening heart failure inpatients for referral to cardiac rehabilitation were predominantly cardiac rehabilitation nurses (38/56; 68%), heart failure nurses (27/56; 48%) or cardiac rehabilitation physiotherapists (7/56; 13%). Coordinators reported different procedures for patients with heart failure compared to those with other cardiac conditions. For example, on the same ward those diagnosed with MI were screened by a cardiac rehabilitation nurse while those diagnosed with heart failure were seen by a heart failure nurse.

Monthly referrals for March 2009 were reported by 190/244; 78% coordinators. Of coordinators recording at least one referral to their general cardiac rehabilitation services, the median number of patient referrals that month was 35 (Interquartile range (IQR) 16, 61). Just over a third of respondents (89/244; 36%) recorded at least one referral for patients with heart failure (median number of referrals for patients with heart failure 3; IQR 2, 6). No coordinators who did not provide heart failure cardiac rehabilitation reported receiving referrals for patients with heart failure.

Cardiac rehabilitation service models for heart failure patients

Phases of cardiac rehabilitation available to patients with general cardiac conditions and heart failure are reported in Table 3. Activities included in Phase III cardiac rehabilitation, the most commonly provided Phase for patients with heart failure, are reported in Table 4.

INSERT FIGURES 3 AND 4 AROUND HERE

Patients with heart failure were mainly (135/244, 55%) invited to attend a mainstream, outpatient group-based programme (mean duration in weeks 8.49 (Standard Deviation (SD) 4.48)), alongside other patients with various cardiac conditions. Few coordinators described heart failure specific outpatient group-based programmes (33, 14%, mean weeks 10.93 (SD 4.36)) or home-based programmes (27, 11%, mean weeks 8.06 (SD 3.30)). The mean duration of a heart failure-specific group-based programme was significantly longer than for patients included in mainstream rehabilitation and for home-based services (mean weeks 10.93 vs 8.49 and 8.06 respectively, $F = 4.038$; $p = 0.019$).

Few coordinators provided home-based services for patients with heart failure (27/244; 11%). The mean number of home visits per patient was 2.84 (SD 2.17). Visits were performed by cardiac rehabilitation nurses ($n = 13$), physiotherapists ($n = 12$) and heart failure nurses ($n = 6$) (categories not mutually exclusive). A variety of home-based cardiac rehabilitation service models were described. For example, 12 coordinators reported telephone monitoring and three reported that home-based rehabilitation consisted exclusively of a telephone service with no visits. Core components of cardiac rehabilitation, such as risk factor monitoring, were less frequently offered in home-based services compared to other group-based models.

Coordinators' views

Near equal numbers of coordinators agreed (36%; 89/244) and disagreed (34%; 82/244) that patients with heart failure should be included in cardiac rehabilitation services alongside patients with other cardiac conditions. Coordinators accepting patients with heart failure to their services tended to agree that they should be included in services alongside other cardiac patients ($\chi^2 = 6.2$; $p = 0.013$). Conversely, coordinators providing separate heart failure services did not agree these patients should be included alongside others ($\chi^2 = 13.2$; $p < 0.001$). Coordinators' commented on the added benefits of group-based exercise classes, such as providing motivation and socialisation, compared to home-based services. However, coordinators described functional barriers may exist for these patients to attend group-based rehabilitation and suggested a variety of service models need to be made available to accommodate patients' comorbidity, decreased mobility and preferences.

Discussion

In 2010, heart failure was estimated to affect around 900,000 people in the UK.¹⁶ We believe this is the first national survey to investigate the process of referral to cardiac rehabilitation for patients with heart failure. It provides a detailed description of the availability and provision of heart failure cardiac rehabilitation in the UK, including coordinators' views about service models. The response rate was high and representative of national service provision.

Despite longstanding national guidance recommending that patients with heart failure should be offered cardiac rehabilitation,¹⁷ this study found substantial gaps in the availability of cardiac rehabilitation across service locations and countries for this patient group. Forty three per cent of cardiac rehabilitation coordinators did not accept patients with heart failure to their services. This finding is higher than recent NACR data⁹ which reported 20% of services did not accept these patients but only audited Phase III. Our study also had wider coverage by including Scotland.

The main reason reported for not providing a service for patients with heart failure was the lack of available funding, i.e. prioritisation by funders of services. This supports previous studies and extensive commentaries about under-resourced cardiac rehabilitation services in the UK.^{14,18–20} Recent commissioning guidance about cardiac rehabilitation services and greater government focus on prioritising heart failure as an area for quality improvement²¹ may help to target funding and resources on rehabilitation including exercise training for these patients.

Extensive exclusion criteria for patients with heart failure restrict access. Coordinators appropriately described excluding patients on the basis of safety, such as those with uncontrolled arrhythmias, consistent with guidance.⁶ However, other locally determined and at times, contradictory, inclusion and exclusion criteria were reported. These discrepancies may be explained by differing awareness or interpretations of the evidence, including the generalisation of results from diverse populations included in clinical trials investigating exercise effectiveness.⁷ Using locally selected parameters such as radiological interpretation of EF and NYHA to determine access to cardiac rehabilitation demonstrates how their use may restrict participation of suitable patients and strengthens the argument for not using such parameters in clinical guidelines.¹

There is particularly limited provision of inpatient (Phase I) cardiac rehabilitation for patients with heart failure. Early invitation and commencement of secondary prevention in hospital is an integral part of cardiac rehabilitation for other conditions such as MI. Patients with heart failure may not be

accessing timely secondary prevention, particularly the benefits of exercise training, unlike other cardiac inpatients.

Those providing cardiac rehabilitation for this clinical group (Phase III) predominantly offered rehabilitation alongside patients with other cardiac conditions. Few offered separate heart failure groups; however, those that did offered significantly longer (approximately 2 weeks) Phase III programmes. Long-duration (> 24 weeks) exercise trials have proved effective for patients with heart failure,²² and these few services providing slightly longer duration programmes may be attempting to apply this evidence.

Few coordinators offered home-based options for patients with heart failure, despite recognising that reduced mobility may restrict travel to outpatient services. A Cochrane systematic review found no difference between home-based and centre-based cardiac rehabilitation in terms of mortality, exercise capacity, most modifiable risk factors, relative risk for proportion of smokers at follow-up and health related quality of life.²³ This meta-analysis was the first to include studies of patients with heart failure, adding to previous meta-analyses for those with stable Coronary Heart Disease (CHD) following MI or revascularisation.²⁴ However, only two of the 12 studies included those with heart failure and more comparative trials to assess the relative impact of supervised centre-based and home-based cardiac rehabilitation in patients with heart failure are needed.²³ Diversity in home-based cardiac rehabilitation service structures and telephone monitoring described by coordinators demonstrate the challenge of defining home-based rehabilitation services and coordinators' perceived definitions may vary.

The referral processes for patients with heart failure were generally underdeveloped compared to other cardiac conditions and were less likely to use automated methods or proactive screening of hospital wards. Lack of automated referral pathways in the UK may contribute to underutilisation of cardiac rehabilitation for all patient groups as methods to improve cardiac rehabilitation referral using electronic referral and electronic prompts have proved effective in other countries.²⁵ Studies investigating the relationships between electronic referral, patient participation and patient outcomes in cardiac rehabilitation are required for patients with heart failure.

Study limitations

The NACR Registry is believed to identify all cardiac rehabilitation service coordinators in the UK. However, it is possible that cardiac rehabilitation services not included on this voluntary register exist. Non-response bias may have occurred despite requests for all coordinators to participate even if a heart failure cardiac rehabilitation service was not provided. We considered our response rate high; however, NACR survey response rates are regularly higher at over 90%.⁹ Responses on service provision were not triangulated for verification but were interpreted in the context of NACR data.

Conclusion

This survey offers some explanation of why so few people with heart failure currently participate in cardiac rehabilitation in the UK. With 43% of coordinators reporting they did not accept patients with heart failure to their services our findings indicated problems with: (a) a lack of available cardiac rehabilitation services for this clinical group; (b) non-systematic referral for patients with heart failure; (c) discrepant and non-evidence based inclusion and exclusion criteria which further restricts access; and (d) wide variation in service models including divided opinion about ideal service structures. For those involved in implementing clinical guidelines and organising heart failure care and cardiac rehabilitation this study provides useful information about service-related factors in need of greater focus if participation of patients with heart failure is to be improved.

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Table 1. Diagnostic groups accepted for cardiac rehabilitation as reported by coordinators.

Diagnostic group	Accepted (%)	Not accepted	Missing ^a
Myocardial infarction	240 (98)	1	3
Coronary artery bypass surgery	240 (98)	1	3
Angioplasty (percutaneous coronary interventions)	226 (93)	12	6
Valve disease or valve repair/replacement	220 (90)	18	6
Implantable devices	168 (69)	65	11
Heart or heart-lung transplant recipients	159 (65)	67	18
Heart failure	139 (57)	94	11
Stable angina	139 (57)	91	14
Other	65 (27)	40	139

^aCoordinators selecting neither or both response categories were classified as missing.

Table 2. Cardiac rehabilitation services and services accepting patients with heart failure by location and country.

Service locality	England <i>n</i> = 189	Scotland <i>n</i> = 26	Wales <i>n</i> = 16	Northern Ireland <i>n</i> = 13	Services accepting patients with heart failure by location <i>n</i> (%)
District general hospital <i>n</i> = 107	88	10	5	4	65(61)
More than one site <i>n</i> = 46	29	10	6	1	20(44)
Acute teaching hospital <i>n</i> = 38	26	3	1	8	23(61)
Community centre <i>n</i> = 37	32	3	2	0	21(57)
Other ^a <i>n</i> = 16	14	0	2	0	10(63)
Services accepting patients with heart failure by country <i>n</i> (%)	111(59)	12(46)	7(44)	9(69)	139

^aMost common response was community hospital.

Table 3. Phases of cardiac rehabilitation provided for general cardiac conditions and heart failure.

	General cardiac rehabilitation service <i>n</i> = 244 (%)	Heart failure cardiac rehabilitation service <i>n</i> = 132 (%)
Phase I	193 (79)	72 (30)
Phase II	212 (87)	86 (35)
Phase III	237 (97)	132 (54)
Phase IV	136 (56)	69 (28)
All four phases	114 (47)	33 (14)

Table 4. Activities included in Phase III cardiac rehabilitation for patients with heart failure (service models not mutually exclusive) reported by coordinators.

Activities included in Phase III cardiac rehabilitation	In mainstream group-based cardiac rehabilitation including patients with heart failure (n = 135) (%)	In exclusive heart failure group-based cardiac rehabilitation (n = 33) (%)	In home-based cardiac rehabilitation for patients with heart failure (n = 27) (%)
Graduated exercise training	133 (99)	33 (100)	25 (93)
Education (e.g. lifestyle advice)	131 (97)	30 (91)	17 (63)
Provision of written leaflets	128 (95)	30 (91)	18 (67)
Risk factor monitoring	124 (92)	25 (76)	13 (48)
Stress management	124 (92)	29 (21)	10 (37)
Relaxation	117 (87)	30 (91)	11 (41)
Other(s)	27 ^a (20)	9 ^b (27)	1 (3)

^aMost frequently the provision of basic life support training; ^bMost frequently energy conservation and symptom management.